

HOW DOES THE BONE CANCER RESEARCH TRUST PRODUCE THEIR INFORMATION?



We are constantly speaking to patients, family members and medical professionals to gain a better understanding of what information those affected by primary bone cancer want and need.

The Bone Cancer Research Trust is the leading charity dedicated to fighting primary bone cancer. In 2016, we became the only charity to provide information on all forms of primary bone cancer. Our wealth of information covering diagnosis, treatment options and clinical trials is accessed by over 211,000 people worldwide annually and allows us to provide patients and family members with an informative and supportive place to turn to on a one-to-one basis.

We aim to provide information that is truly required and will make a difference to those affected by primary bone cancer. We hope to provide knowledge, guidance and empower patients to make decisions on their treatment and care; no matter the rarity of their tumour.

Accessibility of Information

Due to the rarity of primary bone cancer, it is easy for patients or family members to find themselves reading scientific reports or clinical reviews when searching for health information online. This form of information is not accessible to all audiences and can be confusing, overwhelming and difficult to digest. At the Bone Cancer Research Trust, we publish our information in an easy-to-follow, structured format, allowing audiences to read sections they find relevant and at their own pace.

All of our information is written in plain English, with the use of medical jargon or confusing terminology removed. Furthermore, our information is available online, as downloadable factsheets from our website and as printed materials; ensuring it is available for all audiences.

CAN YOU HELP US REVIEW OUR PATIENT INFORMATION?

Our 'Information Advisory Panels' are open to anybody affected by, or working with, primary bone cancer. This includes patients, carers, family and friends as well as medical professionals caring for patients and scientists researching this field. For more details on how to get involved, email us at info@bcrt.org.uk



Look out for The Information Standard logo. This kite-mark ensures the information you are reading is accurate and reliable.

Quality of Information

At the Bone Cancer Research Trust we pride ourselves on the quality of our information. We have been accredited by The Information Standard since 2011 and are reviewed annually to ensure we are continuing to reach this high standard of information production.

All of our information is written using current and credible sources and reviewed by medical professionals and scientists working with primary bone cancer to ensure its accuracy and clinical relevance.

Our information then undergoes a further review by those affected by this disease, including patients and family members, to ensure it is accurate to personal experiences and meets the needs of this audience.

CONTACT US

©Bone Cancer Research Trust 2017

10 Feast Field

Horsforth

Leeds LS18 4TJ

www.bcrt.org.uk

[@BCRT](https://twitter.com/BCRT)

[f/BoneCancerResearchTrust](https://www.facebook.com/BoneCancerResearchTrust)

[0113 258 5934](tel:01132585934)

Charitable Incorporated Organisation (CIO) Number - 1159590

OUR TOP TIPS FOR FINDING HEALTH INFORMATION YOU CAN TRUST.

It can be difficult to find reliable and trustworthy information on the internet, think about these questions before using the information you've found.

Is the website familiar?

When searching for health information, it is best to start with websites that you recognise or that are well-known organisations; such as the NHS or Macmillan. These often provide links to other trustworthy websites too.

Charity organisations are another great place to look and their website addresses tend to end in .org, or .org.uk - so look out for these.

What's the date?

Some information you come across may not have been updated for a while, making the information out-of-date and possibly inaccurate or no longer relevant. If the date on the website page is older than 3 years, it's best to look elsewhere.

Have you cross-checked?

If you see the same information on more than one website, it is more likely that this information is accurate. Look around for information rather than taking it all from one place.

Are there references?

Websites providing information should have a visible list of the references used to produce this resource, or the contact information needed to request these. This is a requirement of The Information Standard.

Can you see The Information Standard logo?

The Information Standard was established by The Department of Health. When you see The Information Standard logo or quality mark, you can be assured that the organisation has undergone a rigorous assessment and the information they produce is high quality.

No information provided online or in printed materials, no matter its quality and reliability, should replace the information and advice given to you by your medical team.

If you read anything you're unsure of, show it to your medical team and ask them to explain it to you.

Is the forum regulated?

Most chat rooms or forums are not regulated or monitored and the people sharing information on them are not experts. These forums can be great for hearing personal experiences but the information they share might not be correct.

Is the website trying to sell you something?

Be cautious of websites that offer information but are also trying to sell you something. Their information is likely to be biased and may not be true. If there is something that you're interested in, it is best to show it to your medical team first.

Is this relevant to your country?

Diagnosis and treatment guidelines may vary from country to country. If you are reading information that is produced in another country, it is best to check that this is relevant to you with your medical team.

Information overload?

There is a wealth of information available online and it can be overwhelming at first. It may be useful to use the information you've found to create a list of questions and topics you'd like to discuss with your medical team.

If you're ever unsure of the information you've found regarding primary bone cancer, or would like some guidance on organisations or websites to use, speak with your medical team or contact the Bone Cancer Research Trust at info@bcrt.org.uk.

Our list of trusted organisations can also be found on our website on our 'Useful Organisations' page.

Visit www.bcrt.org.uk/usefulorganisations



CONTACT US

©Bone Cancer Research Trust 2017

10 Feast Field

Horsforth

Leeds LS18 4TJ

www.bcrt.org.uk

[@BCRT](https://twitter.com/BCRT)

[f/BoneCancerResearchTrust](https://www.facebook.com/BoneCancerResearchTrust)

[0113 258 5934](tel:01132585934)

Charitable Incorporated Organisation (CIO) Number - 1159590